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ABSTRACT

This report describes Neighbours, Inc., a nonprofit organization based in Franklin Park, New Jersey, that offers individualized supports for people with disabilities. In addition to the CEO and the director, the agency employs five advisors. These advisors each work to coordinate support for between five and seven people. Advisors, who typically have contact with the people they support at least once a week, provide a variety of supports including hiring personal assistants, working on scheduling and managing personal assistance services, looking for job opportunities, and building social networks. This report discuses the organization structure of Neighbours, how the agency provides supports toward full community life, housing supports, daytime supports, assisting individuals in expanding their social networks, advocacy efforts, and service brokerage. Critical factors to the success of Neighbours are identified and include: (1) linking agency practice to philosophy; (2) providing creative solutions to individual situations; (3) devoting resources to relationships and quality lives; (4) having a commitment to finding the funding to support integrated lives; and (5) using the best technology possible to help individuals achieve autonomy. Challenges to the program are also discussed and include dealing with the state bureaucracy and finding quality personal assistants. (CR)

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SHIFTING FROM EMPOWERED

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TO EMPOWERED PEOPLE:

NEIGHBOURS, INC.

by

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Note: With the exception of Patti Scott and Kenn Jupp, all names used throughout this report are pseudonyms.

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Background/Introduction

Neighbours, Inc. is a nonprofit corporation based in Franklin Park, New Jersey. As stated on their web site, this organization "has been formed for the sole purpose of enabling people who have disabilities to have a full and exciting life within their local communities." In order to do so, Neighbours focuses on assisting people to have increased control and choice in their lives, irrespective of the extent or nature of their disability.

Neighbours, Inc. was formed in 1995. One of the founders, Kenn Jupp, had previously worked in England moving children from segregated to inclusive schools. The other, Patti Scott, had worked in an agency in New Jersey, where she tried to make changes that would shift the emphasis from facility-based support to more individualized forms of support for all people with disabilities, including those with the most severe disabilities and challenging behaviors. Frustrated by these efforts to change more traditional agencies, they decided to form their own agency so they could offer supports that would give people increased choice and control. They were inspired in their efforts by their familiarity with other agencies that offered individualized support, as well as by their connection with others in the field of developmental disabilities who promote individualized supports and full inclusion for all.

Based both on what they had experienced as being negative about traditional services, as well as their vision of a more positive way to support people, they formed the agency around several core principles or values. These include:

- Stop empowering agencies and their staff. Start empowering the person and family.
- Stop looking at what is wrong with the person. Look at what the person has to offer.
- Stop focusing on people's needs. Start listening to what people say. Help people build their life and pursue what they are excited about.
- Stop using things that are unnatural in helping people develop connections. Try to help people have real friends.
- Get away from people being in separate places. Try to help people have jobs and interesting things to do in the community.
- Keep moving forward. Handle the daily problems while still devoting time to assisting individuals and the agency as a whole to move toward a desirable future.

Organizational Structure

Based on the founders' past experiences with agencies that were controlling people's lives and using significant resources for an agency office and administrative costs, they selected an alternative model for their service--that is, a small corporation that operates as a "virtual" agency, with no office. Instead, all employees are given laptop computers, cell phones, and fax machines. As a corporation, they see themselves as the agent for the people they support.

Staff include Patti, who is the CEO, or Executive Director, an agency director, and five advisors. The role of CEO of Neighbours, Inc. has included both significant involvement with most of the people whom the agency supports as well as with agency administration. It has involved planning with most of the people whom the agency supports, putting together funding

proposals, and advocating for state Division of Developmental Disabilities approval of these proposals, when necessary. Patti oversees the work of the director and the advisors through regular meetings as well as phone and e-mail contact. In addition, she oversees agency operations, including internal paperwork, such as monthly budget reports for the people they support, as well as external paperwork, such as documentation required by the state. Finally, as needed, she meets with local, regional, and state administrators to advocate on behalf of individuals or the agency as a whole.

The current agency director has been in this position since April 2001; she has worked for Neighbours since December 2000. Patti explained that in the past they hired people whose main strength was their values, personal relationships with people the agency support, and ability to assist those people to connect with others. However, this led to some shortcomings on the organizational and administrative end. As a result, the current director was hired for her strengths in organization and administration; however, her values and ability to connect with others were important as well. Part of her role is to work as a liaison between the people who contract with Neighbours to provide support and the state. Under Patti's mentorship, she is taking on new areas of responsibility with regard to her involvement in helping put together funding proposals and other paperwork. In addition to her administrative work, the director coordinates monthly meetings of all of the advisors, visits everyone whom the agency supports on at least a monthly basis, and attends occasional meetings pertaining to people's support or other issues.

In addition to the CEO and the director, the agency employs five advisors. These advisors each work to coordinate support for between five and seven people. Advisors typically have contact with the people they support at least once a week, if not more. They assist with

whatever the person would like. This can include: hiring personal assistants, working on scheduling and managing personal assistance services, looking for jobs or volunteer opportunities, building social networks, and so on. In addition, advisors have significant contact with families, personal assistants, case managers, and others who are involved in some way with the person. Advisors arrange for regular meetings with the person and those closest to him or her for ongoing communication, future planning, and to work out any problems that arise.

Supports Toward a Full Community Life

As previously stated, Neighbours staff see themselves as an agent for the people they support. Upon request, agency staff will meet with a person and describe what kind of supports they offer. If the person then selects Neighbours, together they will write up a support proposal. Patti emphasizes her focus on capturing the person in this plan, using narrative and pictures. Upon approval of the plan, the money comes to the person through the agency, with a separate budget line in the agency contract for each person. Each person can determine how they want to spend their money, as long as they stay within their overall budget.

Altogether, Neighbours supports 32 people; most people request residential as well as daytime support, although a small number request one or the other. They are committed to staying this size, as they feel they would be in jeopardy of being too bureaucratic and losing their person-centered quality if they were much larger.

In general, once a funding proposal is approved, the support that Neighbours provides to people involves a number of different components, such as: assisting people to find housing and support; assisting people to find work and other meaningful things to do during the daytime; and assisting people to develop relationships and circles of support. Across all of these areas, both in the support planning and implementation stages, Neighbours emphasizes their role as an

advocate with and for people. Finally, through a subcontract with an affiliated agency, Neighbours offers service brokerage for those people interested in this means of obtaining support. Descriptions and examples are given below.

Housing and Support

One of the primary focuses of Neighbours is to assist people to live in homes of their own, with whom they want, with choice and control over the supports they receive to do this. Many of the people who are supported by Neighbours previously lived in institutions, nursing homes, group homes, and other facilities for people labeled mentally retarded. With support from Neighbours, they now have a broad range of living arrangements, including apartments, condominiums, and houses that they rent or own, in which the live on their own or with housemates. Some housemates provide support in exchange for rent, whereas others share the house and pay rent.

For support, advisors assist people in all aspects of managing personal assistance (PA) services. Many of the people who Neighbours supports have never previously had an opportunity for this degree of control, so it is a learning process for them about rights and responsibilities, as well as relationships with PAs.

Each person has a primary, or senior, PA; most are full-time, though some are part-time. Some senior PAs have also been housemates, while most have not. Many people also have a few other full- or part-time PAs. PAs report both to the person and the advisor. While the PAs are legally employees of Neighbours, the people who contract with Neighbours are their managing employers--"they decide to hire/fire them, to give them raises or bonuses, they do their evaluations with the support of an advisor." PAs assist people with whatever they would like assistance with, ranging from personal care, to household maintenance, shopping, banking,

volunteer work, socializing with friends, and so forth. In cases where people have more than one PA, the senior PA helps to organize and manage the support provided by the team of PAs. Advisors assist with this as well.

Martha is a woman in her mid-30s who has received support from Neighbours for approximately four years. She lives in her own two-bedroom ground floor apartment in a multiunit apartment complex. It is located in an exurban area which is a mix of housing developments, expanding shopping areas, and open fields. The apartment is comfortably furnished, and the décor includes pictures, plants, and numerous photos of Martha engaged in a variety of activities with support staff and friends. Trish, who is her senior PA, currently shares the apartment with Martha; she lives there rent-free in exchange for her support. Trish is with Martha from the time she gets up until 4:00 pm. Another PA comes in at 4:00, assists Martha with evening activities, and stays until around 11:00 pm, after which time Trish again provides support. Additional staff cover the weekends when Trish visits her family in New York. Martha and Trish spend their days at the pool, the park, shopping, or taking care of household chores. Martha enjoys riding her bike, playing cards, visiting the mall or pet store, or going out for Chinese food.

Martha lived in an institution from the time she was 6 years old until she was 32. In the institution, she often expressed her anger and frustration by pulling pieces of hair and scalp from her staff members or visitors. Because of this, when the institution she was in closed, Martha was considered dangerous and it was likely that she would be sent to a locked group home. However, her state appointed guardian strongly felt that congregate residential or day services would be detrimental to Martha. As an alternative, her guardian helped her obtain support from Neighbours. The funding provided for Martha was not quite sufficient to meet her needs.

Neighbours supplemented Martha's budget in order to provide supports, rather than forcing her to go to a workshop or day habilitation center.

Since she has been living in her own apartment, Martha has fewer occasions of intense anger. When this does occur, she has learned to exercise restraint, and now, when she feels like pulling someone's hair, she will instead ask them to tie their hair back or put on a hat. When she first moved, she was not comfortable around many people, and was fearful of riding in cars. Now, she is much more comfortable with people and in cars. She enjoys people, making friends easily and retaining them. At her recent birthday party she had an apartment full of guests. She has no contact with her biological family, but has made a family out of her current and former support staff, with frequent invitations to staff members' family events or houses for weekend visits. One of Martha's friends, Laurie, is applying for guardianship, as her state appointed guardian is leaving his job. Laurie was Martha's advisor from Neighbours, and has stayed close to Martha, inviting her to spend a week each summer with her family in their beach home.

Martha volunteers once a week at a local soup kitchen. Trish is assisting her to explore other work interests. At this point, in order for Martha to work at all, she needs a job which is flexible enough so that she can take a break from it when she needs to. She is learning to bake, and finding that she really enjoys that activity. Because of her ability to warm up to people quickly, and her love of baking, Martha's support staff are trying to help her find a way to create a small business out of baking and delivering food to people. They feel that a job such as this, that combines her talents and interests with flexibility, would be ideal for her.

Daytimes

If requested by the people they support, Neighbours, Inc. will include in their proposals a request for funding for daytime supports, as an alternative to sheltered employment or a day habilitation facility. For a number of people, they have been successful in this request.

Some people who are supported by Neighbours have, at the outset, specified that they want to stay in their day program. Patti explained that, in these cases, Neighbours staff make an effort to help people see that there are other options. This is sometimes a process of discovery for people. She described Tim, who had in the past been kicked out of group homes and other facilities; she said the one place he felt had stuck by him was his day program. Therefore, when Neighbours first began supporting him, he moved into his own apartment, but wanted to continue at the day program. Within about a year of moving to his apartment, he found a part-time job and cut back on the day program, and within a couple of years, he had full-time work and stopped going to the day program altogether.

Some people who request Neighbours' support during the daytime have clear ideas about what they would like to do. For instance, Doug moved from a nursing facility into his own apartment in 1996. He was the first person that Neighbours assisted. He is an artist, doing hand-painted and computer-designed greeting cards which he sells at crafts fairs. Doug would like to expand to full-time work in this business, and, as part of this, would like to start an artists' cooperative. His advisor is currently assisting him to look into this.

For others who the agency supports during the daytime, it has been a process of figuring out what sorts of work and other daytime engagements are best suited to the person. For Chris, this process entails gradual exploration with Chris, with significant collaboration between his

mother, his advisor, and his team of PAs, all of whom have some differing as well as many shared visions of Chris's future.

Chris's mother, Helen, recalls, "When he was young, he was in an integrated preschool and he did fine. He started having problems when he was classified and separated...He was also accepted as part of the neighborhood by other children and families." After he moved out of his mother's house, he lived in a group home. However, his mother was extremely dissatisfied with this. She says it took a 3-year battle with the system in order to get him out of the group home. She heard about Neighbours through a friend, and approached them about supporting Chris.

For four years, now, Chris has lived in a condominium owned by a trust that his mother established for him. With regard to this, Helen comments, "Now he has a home and property that no one can take away from him." He has 24-hour support provided by four young men. Even though it is more difficult to find men, Neighbours has worked to honor Chris's preference for male PAs. In addition to the four PAs, Hannah, his advisor from Neighbours, is in contact at least weekly. She occasionally fills in to provide direct support.

In the summer, one of Chris's favorite things to do is go swimming and hang out at the pool that is part of this condominium development. Through this, he met a neighbor, Lucy, along with her husband and son, and they have become friends. In addition to seeing Chris at the pool, they sometimes invite him to their home or come to visit him. Other things Chris enjoys include going to amusement parks, to the YMCA, and out to lunch. Due to his visual impairment, staff are assisting Chris to increase his independent mobility with use of a cane. In his home, he enjoys playing his electric keyboard and listening to music. Chris uses a communication board, and is working with a speech therapist to increase his verbal communication.

Helen is particularly pleased that Chris has 24-hour support from Neighbours and does not have to go to a day program. At the same time, Chris's support staff feel that, particularly in winter, he spends too much time sitting at home, and they are trying to think of work options as well as other activities that would be of interest to him. His recently acquired minivan, which is driven by support staff, should increase some of these options.

Helen still sometimes struggles with the realization that living with staff is not the same as being surrounded by loving family. In the past, Chris had negative experiences with one of the PAs. However, at the present time, Helen feels positive about the team of supporters surrounding Chris. She feels he is very content with his life now because he has more control in his life, and because he has caring, consistent relationships with the people who support him. Over time, as he has settled into this home and gotten to know Neighbours, Helen sees glimpses of his earlier life, as part of the community, returning.

Relationships

Staff at Neighbours, Inc. believe that the most important thing for people is "having people in your life who care." To this end, Neighbours has assisted many of the people they support to develop circles of support and increase their social networks. One example is Jeff, who owns a home near a university. One of his previous respite workers, who was a student at the university, assisted Jeff to develop a circle. She began by inviting some of her friends to gatherings at Jeff's house, where they would have pizza and hang out. Over time, as these friends got to know Jeff, one of them started coming over on another night to do puzzles with Jeff, and another helped him set up a woodworking shop in the garage and spent time with him there a few times a month on the weekends.

Overall, there is the acknowledgment that helping people to have community connections and friendships is slow, ongoing work. For instance, according to Patti, with Jeff, the network of friends took months and months to establish, and once those college students graduated, they moved on, and a renewed effort was needed to assist him to find new friends. Agency staff feel they have made progress in helping many of the people they support make connections, but that they still struggle in doing this for some people.

They acknowledge the danger in getting caught up in attending to administrative work and neglecting those aspects of support that enhance people's quality of lives. Thus, they always try to keep focused "on some of the things that are important...we always try to make sure we put some time into the stuff that helps people have nicer lives." As part of this effort, in the past year, they have changed the roles of a person who was previously an advisor, and who is skilled at assisting people to make connections. She is still an advisor for a few people, but will also focus on assisting some people to build support circles, and on assisting other staff to support people in doing so.

Advocacy

As part of their work, staff at Neighbours advocate with and for people in many ways. For instance, advocacy is often used with regard to funding proposals, guardianship issues, and bureaucratic rules and regulations. As Patti put it, "One of the keys is not getting sucked into the system; remaining aware enough to know enough to stay on top of things, so people can remain in control of their money and their lives." As part of this effort, Neighbours staff work to build collaborative relationships with case managers, state administrators, and others. The agency director explained that, in their advocacy, they try to help others involved in disability services to

understand the importance of choice and control. She feels that, while they have educated many people about this, "we still have a lot of convincing to do."

One example of advocacy involved a woman named Gloria. Neighbours staff met Gloria at an institution when she was 78 years old. "She had lived there for 50 years; they were closing the institution, and she didn't want to move, she didn't want to talk to anyone, she wanted to be left alone and stay there, no matter what." According to staff at Neighbours, Gloria was resistant to getting to know them and to talking about moving. One of Gloria's potential PAs learned that Gloria loved animals, and so she brought her a cat. This began a connection between Gloria and the Neighbours staff member, Joan. They worked on a funding proposal. Gloria wanted to move to the same town where her brother lived. They had only seen each other about four times in the past 40 years, but felt a strong connection with one another.

In November 1997, Gloria moved into the bottom floor of a two-family house. At the time of her move, Gloria was clear that she wanted to keep going to a senior citizen day program. But, as Patti explained, "She was in the house about a half an hour and said, 'I'm not going to the day program.'" The agency did not have funding for day services for Gloria, but decided to use other resources in order to provide her support in the daytime rather than force her to go to a day program. As Patti put it, "This past June we finally got the funding to support her in the day time, but we had figured out how to make it happen in the mean time, because when you're 80 years old, no one should make you go somewhere because they don't have money for it." So, Gloria spent her time going to pet shows, flower shows, arts and crafts fairs, and other community events. In her home, over time, she acquired a cat, a dog, a rabbit, three birds, and a turtle.

Over the summer of 2001, Gloria was sick, and eventually ended up in the hospital, where she was put on a feeding tube. Patti explained, "After that, regulations prohibited her from returning to her home, so we spent about 2 months fighting for her to go back." The issue was that the state Board of Nursing required nursing care for someone with a feeding tube. A new law was being enacted in September that would allow the nurse to delegate the feeding tube responsibility to the person, who would then delegate it to his or her support staff. A barrier to allowing Gloria to do this was that she was not her own guardian. Neighbours staff and her guardian advocated strongly for Gloria with the Board of Nursing. Eventually, it appeared that the issue had been resolved and that within about 2 weeks it would be possible for Gloria to go home. However, Gloria died that night, in the rehabilitation hospital. She would have been the first person in New Jersey to go home under these circumstances.

Service Brokerage

The New Jersey Self-Determination Project has worked to make service brokerage available in the state. In conjunction with this, Neighbours offers service brokerage, an initiative that is part of the agency as a whole, but operates separately. On her own, on a consultant basis, Patti is a broker for 19 individuals. In addition, there is a small brokering organization affiliated with Neighbours that provides service brokerage for about 30 people.

The brokering supports are similar to the other supports that Neighbours provides. However, the funding goes through a fiscal agent, rather than through Neighbours, and the person's budget and contract is not with Neighbours (though there is a contract with Neighbours for the brokering services), so Neighbours is not legally responsible for the staff. Additionally, Neighbours has established an Association of Independent Support Brokers in three counties in Pennsylvania. The counties contract with Neighbours for these brokerage services. Neighbours

employs directors in each of these counties. The directors oversee a wide range of aspects of brokerage services including: providing brokerage themselves; recruiting brokers; providing a register of brokers; providing ongoing training, mentoring, and support to brokers; and facilitating circles of support. Additionally, they created a code of ethics for brokers; act as independent moderators if people are having conflicts with a fiscal agent or broker; and develop publications/promotional materials regarding self-determination. Each county has its own advisory group for the brokerage project, and different ways of implementing it.

Patti also allocates a portion of her time to each of those counties. She meets with and oversees the work of the three county directors. In one county she has been facilitating meetings with case managers in order to promote further understanding of and collaboration with self-determination efforts. Also, she has worked to develop a booklet that explains self-determination to people with disabilities and families, and Neighbours has written a manual for brokers.

One person who Patti brokers for is Nancy, who is 32 years old. Nancy grew up in a large family with her parents and six brothers and sisters. Though Nancy was enrolled in an integrated high school, she recalls those years as miserable ones due to the teasing she endured because of her disability. After high school, her parents placed her in a "transition home." Nancy strongly resented being segregated in a house with others with disabilities, and she came to view that house as a "jailhouse" because of the restrictions and limitations that were placed on her. She moved back in with her parents and was placed on a waiting list for residential services by the state of New Jersey. At this time she got a secretarial job at the United Way, with job coaching support from the Arc. From this job, she moved to a secretarial position at the Sisters of Mercy convent. When residential services were offered to her, Nancy and her parents decided

to seek these services through the state self-determination initiative, rather than a traditional agency. They met with Patti and began working with her as a service broker. Initially, Nancy and her parents were thinking of finding a condominium and hiring one or two support staff. However, just as they were about to submit this proposal, another possibility occurred to Nancy.

Nancy says that, "Since I was eight years old, I wanted to become a Sister." She had been doing secretarial work at the Sisters of Mercy convent, and raised the idea of moving into the convent. Her parents met with the President of the order. The convent had never had a resident who was not a nun, but the President was open to the idea. Patti met with her to work out some of the details. For instance, since Nancy is not a nun, she would need to contribute money for room and board. Patti arranged that this payment would be made from the fiscal agent that handles money for people involved with self-determination.

Nancy moved into the Sisters of Mercy convent on December 11, 1999 as a "Mercy Associate." She lives in a dormitory with approximately 80 nuns. She has a small, private room, which includes her bed, desk, computer, bookcase, and numerous pictures and other personal items. Nancy's daily routines with the nuns include prayer, meals, meetings, watching the evening news, and Friday movies. When asked about her life with the nuns, Nancy emphasizes, "A Mercy Associate is a person within the sisters and they have to do anything and everything a sister has to do."

During the daytimes, Nancy does reception/secretarial work in another building on the convent grounds. She works from 11:30-4:00, Monday through Saturday. She is paid for her work during the week, and volunteers her time on the weekend. She no longer needs the assistance of a job coach. In addition to this work, Nancy regularly visits some of the nuns who reside in the medical unit.

Patti has also worked with Nancy to find support staff. At first, Nancy did not want support staff. However, Patti encouraged her to try it, as she knew that Nancy had a variety of interests beyond the convent. Nancy agreed to try it for 10 hours a week. Nancy and Patti wrote a notice and flyer in order to advertise the position. Since Nancy moved to the convent, she has had three different support staff; one was found through advertising and the other two through personal connections of Neighbours staff. The first person turned out not to be a good match, personality wise, so Nancy let her go. She then hired Ann, who worked out well for quite awhile. In fact, Nancy enjoyed this so much that the next year she asked for two more hours of time per week in her budget for Ann. Eventually, Ann and Nancy began to have difficulties in their relationship. Nancy felt that Ann brought her problems to work with her too much. In addition, Nancy acknowledges that her frequent phone calls, sometimes expressing anxiety and anger at Ann, may have been difficult for Ann. Since Ann resigned, she and Nancy have been able to resolve some of their differences and remain friends. As she began searching for her third support person, Nancy requested the time be increased to 14 hours per week. Patti explained that by cutting in another area of Nancy's budget they were able to make this increase. The current support person is Peg, and Nancy is enjoying her time with Peg. Nancy enjoys doing many types of things in the community such as water aerobics, movies, university basketball games, and going out to eat.

Over time, Nancy has been able to more clearly define what she is looking for in a support person. For instance, when asked what was most important to her, she said, "Someone who plays music low, somebody who helps me with the seatbelt, somebody who doesn't smoke, somebody who doesn't bring their problems to work and lay it on me." She has also come to the realization that each support person may have some positive and negative aspects to them, and

that she has to weigh all of these together. Patti has told Nancy that Nancy can call her at any time with questions or to express concerns or frustrations. Nancy calls Patti about once a week, depending on how things are going in her life. One frustration was the amount of time it took to find a new support person after Ann left. In particular, without the support person, Nancy could not participate in water aerobics, as she needs someone there in addition to the instructor in case she has a seizure. Occasionally, Patti accompanied Nancy to water aerobics when she was between support people.

Nancy's family lives nearby, and she sees them regularly. Some of her siblings are hesitant to visit the convent; others are not. One brother comes regularly to help her with banking. Although Nancy considers her parents to be very supportive, she has also been trying to attain more independence from them. For example, this year was the first time she went to her annual service plan meeting with Patti but not her parents. This was a very significant step for her.

On Tuesdays, Nancy regularly goes out to dinner with a friend, Sherry, who she has known since high school. On her own, in her free time, Nancy enjoys using her computer. She particularly enjoys participating in a religious chat room, where she has met a couple of people who she keeps in touch with on a regular basis. At holiday times, Nancy enjoys making chocolate in molds and giving it as gifts to friends and family members.

Overall, Nancy says she loves living here. She sees it as an arrangement of mutual benefit, in which she is given support by some of those she lives with at the convent and she provides support and assistance to others there.

Strengths and Challenges

There are many strengths of Neighbours that enable them to support adults with severe disabilities in having choice and control in their lives. Like any agency operating in the realities of today's culture, Neighbours also faces challenges in implementing its vision of supporting people to have quality lives in the community. Some of these strengths and challenges are discussed below.

Linking agency practice to philosophy. One of the strengths of Neighbours is the closeness to which they stick to their underlying philosophy. Patti said that she and Kenn founded Neighbours to "stop empowering agencies and their staff and start empowering the person and the family." To a great extent, Neighbours has been able to do just that. For example, according to Patti, because of rules and regulations that have been imposed on self-determination efforts within the state, people who are supported by Neighbours currently have more control over how they spend their money than do those participating in the self-determination project.

Creative solutions to individual situations. The philosophy of Neighbours encourages them to look creatively at solutions to individual situations. They work to see the individual as a whole person, rather than the disability as a deficit. Martha enjoys baking and talking to people, however, she is not always able to work a fixed schedule. So, rather than push to fit Martha into a job or program that she would likely "fail" at, they are seeking options that both interest her and offer the flexibility she needs.

Devoting resources to relationships and quality lives. Neighbours believes that relationships and other positive experiences are essential to a quality life, and they are committed to devoting agency resources to assist people in these areas. In particular, staff of Neighbours

continue to work on helping people to have friends who are not members of their staff. One specific step in this direction, as noted previously, is rearranging staff roles in order to put more energy into building relationships and support networks for those who desire this.

Commitment to find the funding to support quality, integrated lives. To begin with, Neighbours' design as a "virtual agency" keeps overhead costs low and allows the greatest amount of money possible to be in the hands of the individuals. At times, people's budgets are still not adequate, such as when it is important for the person to live alone rather than share a home, or when requests for funding of day services are denied but the person would have difficulty going to any of the existing day services programs. In these cases, the agency uses its own funds to supplement individual budgets. Funds from the service brokerage and other training and consultation efforts are channeled back into the agency to help with this.

Additionally, local public transit in this area of New Jersey is not adequate to give people with limited mobility the opportunity to pursue jobs, social relationships, and other interests outside of their immediate geographic area. Neighbours has solved this problem by finding funding for a vehicle for almost everyone who needs this. They have also worked with the insurance companies to make it permissible for anyone to drive the vehicles. This allows PAs, family members, or friends to drive, and gives people full freedom of movement.

Using the best technology possible to help individuals achieve autonomy. Solutions range from the simple to the more elaborate. Chris has recently obtained a new assistive communication device and is in the process of learning to use it. The staff was patient as they all worked consistently with Chris to learn the new device. Additionally, Patti told of one person who wanted time alone during the day, but was worried about falling or having some emergency. For this individual, they obtained a large button alert bracelet that she can activate by hitting her

wrist against her wheelchair or any object. This gives her peace of mind when she is home alone.

In implementing its vision, Neighbours also has its share of challenges. Two of the major ones include dealing with the state bureaucracy and issues related to personal assistance services.

Dealing with the state bureaucracy. Staff at Neighbours find it time consuming to always be advocating vis-a-vis the state bureaucracy around funding and other issues for the people they support. One such issue is related to licensing. About half of the people whom Neighbours work for must have their homes licensed by the state. The licensing inspections are geared toward administrators of facilities rather than individuals in their own homes. Overall, staff at Neighbours feel that they have to continually engage in the work of educating others in the state about their approach; while some people have come to understand, there are many more who still do not.

PA issues. One of the biggest issues is difficulty finding quality personal assistants. When people have to pay overtime to PAs because of a shortage of staff, their budgets are stretched. Neighbours addresses this issue in a number of ways. For instance, the agency is committed to helping people retain good staff; this may involve things such as flexibility about schedules and personal life circumstances. In addition, Neighbours works toward creative solutions; for instance, if the person is entitled to home health care hours, the PA sometimes can become an employee of the home health care agency.

Overall, Neighbours' focus is on assisting people to live full lives in the community. They believe that, in order to do this, people need real power and control. One of the most flexible options available to many people with disabilities has been personal assistance (PA) services. However, access to PA services has been very limited for people who might need

assistance in managing these services. Neighbours has provided access to PA services for people with the most severe disabilities, by assisting them to direct these services, within the context of a network of supportive staff, friends, and community members. Also, based on their belief that people need real choices, Neighbours has made efforts to ensure that different options for control, such as service brokerage, are available within the state. This work is challenging due to the constraints that still exist within the system. In order to meet this challenge, two commitments are key: that Neighbours has a commitment to stick with people as they work through the challenges that confront them in gaining personal power and control; and that Neighbours has a commitment to advocate for systems level change that supports further empowerment of individuals and less empowerment of agencies and bureaucracies.

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